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ABSTRACT

Presented is an overview of issues and concepts related to deinstitutionalization and the development of community based services for the mentally retarded. Explained are distinctions between mental retardation and developmental disabilities, and between decentralization, deinstitutionalization and institutional reform. Forces in the deinstitutionalization movement are analyzed, including normalization and legal action. Resistance by parents and economic interests are said to be among barriers to deinstitutionalization. Elements of a comprehensive service system, including adherence to a developmental model are considered, and comprehensive system services such as family support and child development services are described. Given are examples of deinstitutionalization efforts in Connecticut, Nebraska and California. Approaches to deinstitutionalization in rural areas receive special consideration. (CL)

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DEINSTITUTIONALIZATION AND THE DEVELOPMENT OF COMMUNITY BASED SERVICES FOR THE MENTALLY RETARDED: AN OVERVIEW OF CONCEPTS AND ISSUES

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PREFACE

The purpose of this report is to present an introductory overview of concepts and issues related to deinstitutionalization and the development of community based services for the mentally retarded. Special attention has been given to deinstitutionalization in rural areas.

Given the fact that mental retardation often involves a birth to death condition, various degrees of handicap, and requires a wide array of residential and support services, this brief report does not pretend to do justice to all facets of this very complex subject area. Hopefully, this report will at least provide the reader with a better appreciation for the many aspects of deinstitutionalization and provide some direction for additional study and exploration.

It should be noted that this report has been prepared for a nonprofessional audience. Professional and technical jargon have been avoided wherever possible.

A DEFINITION OF MENTAL RETARDATION

In order to comprehend some of the problems and issues surrounding deinstitutionalization and the development of community based services for the retarded, it is necessary to understand certain mental retardation concepts. Below several quotes have been drawn from a standard reference book prepared for the American Association on Mental Deficiency by Grossman (1973).

> Mental retardation refers to significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period. (p. 11)

The development period extends to 18 years of age. The term adaptive behavior refers to:

> ...the effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his age and cultural group. Since these expectations vary for different age groups, deficits in adaptive behavior will vary at different ages. These may be reflected in the following areas:
>
> During infancy and early childhood in:
> 1. Sensory-motor skills development and
> 2. Communication skills (including speech and language) and
> 3. Self help skills and
> 4. Socialization (development of ability to interact with others) and
>
> During childhood and early adolescence in:
> 5. Application of basic academic skills in daily life activities and
> 6. Application of appropriate reasoning and judgment in mastery of the environment and
> 7. Social skills (participation in group activities and interpersonal relationships)
>
> and
>
> During late adolescence and adult life in:
> 8. Vocational and social responsibilities and performances
>
> (p. 12)

It must be emphasized that mental retardation consists of deficits in <u>both</u> intellectual functioning and adaptive behavior.

> Both the intellectual level and the adaptive behavior level should be considered in making classifications. While it is recognized that there is a positive correlation between intelligence and adaptive behavior, demonstrations of variability in individuals indicate that separate measures are warranted. Only those individuals who demonstrate deficits in both measured intelligence and adaptive behavior are classified as being mentally retarded... (p. 13)

The emphasis placed on adaptive behavior is relatively new to the conceptualization of mental retardation. In the past, the classification or diagnosis of mental retardation rested almost exclusively on measured intellectual functioning.

A wide range of data (test data, clinical observation, social history, observation of everyday behavior, etc.) should be utilized in the diagnosis of mental retardation. A single source of data (e.g., an I.Q. score) should not be used to establish a diagnosis of mental retardation. For these reasons multi-disciplinary teams should be involved in the diagnostic process. For example, diagnostic teams should consist of physicians, speech and hearing specialists, social work specialists, psychologists, learning disabilities specialists, public health nurses, etc.

It is also important to distinguish between the cause or etiology of mental retardation and the condition itself. There are, for example, over 200 known causes of mental retardation.

> Mental retardation as defined, denotes a level of behavioral performance without reference to etiology. Thus, it does not distinguish between retardation associated with psychosocial or polygenic influences and retardation associated with biological deficit. Mental retardation is descriptive of current behavior and does not imply prognosis. Prognosis is related more to such factors as associated conditions, motivation, treatment and training opportunities than to mental retardation itself. (Grossman, 1973, p. 11)

The American Association on Mental Deficiency recommends that the terms mild, moderate, severe and profound be used to describe various levels of retardation. Among those considered to be mentally retarded, approximately 89% fall into the 'mild' category, 6% are 'moderate,' 3.5% are 'severe' and 1.5% are 'profoundly retarded.

It is commonly assumed that approximately three percent of the general population is mentally retarded. The National Association of Retarded Citizens (NARC) and the President's Committee on Mental Retardation (PCMR) are but two of the many organizations which base their program and service recommendations on the three percent prevalence rate. However, not everyone accepts the three percent figure. Mercer (1973), for example, has argued that the three percent rate is based on faulty statistical and definitional assumptions and does not conform to empirical data. She believes the prevalence rate is closer to one percent. Edgerton, Eymon and Silverstein (1975) observe that:

> It may be correct to state that three percent of the children born will be diagnosed as retarded at some time during their lives. But this is not true on any given date; the correct figure is closer to one percent. This is so because people who were diagnosed as mildly retarded during childhood or adolescence appear to be quite normal as adults. Similarly, it is often difficult to identify mildly retarded preschool children because their behavior is often like that of other children. Mental retardation should not be considered an unchanging or a permanent condition.

It has been estimated that about 25 percent of the mentally retarded in the United States are found in various types of institutions. Many of these, however, are not 'labeled' retarded and most are not in institutions for the mentally retarded. A large number are to be found in nursing homes, hospitals for the mentally ill and correctional institutions. For example,

in 1971 "...almost 30,000 residents in state mental hospitals were diagnosed with mental deficiency as the primary disorder." (Mental Retardation Source Book, 1973, p. 3) About ten percent of the retarded are in institutions for the mentally retarded. In 1971 about 28,000 were in private institutions and approximately 181,000 were in public institutions for the retarded.

DEVELOPMENTAL DISABILITIES

Increasingly, the term developmental disability (D.D.) is used as if it were synonymous with the term mental retardation. To avoid confusion, it is important to distinguish between the two terms. All mentally retarded individuals are developmentally disabled but not all developmentally disabled persons are mentally retarded. The term developmentally disabled is more inclusive than the term mental retardation and is a legal definition rather than a clinical definition. Below is a fairly typical definition of developmental disabilities. It appears in the Montana Developmental Disabilities Services and Facilities Act of 1974.

> Developmental disabilities means disabilities attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other neurological handicapping conditions closely related to mental retardation and requiring treatment similar to that required by mentally retarded individuals; which condition has continued or can be expected to continue indefinitely and constitutes a substantial handicap of such individuals.

It is important to note that some states do not include autism in their D.D. definition and in some states serious consideration has been given to the addition of learning disabilities to the definition. Thus, the term developmental disabilities lacks precision and is a source of some confusion.

DEINSTITUTIONALIZATION: GOAL AND PROCESS

As used here, the term deinstitutionalization refers to both a goal and a process. As a goal, deinstitutionalization refers to a planned reduction in the number of persons residing in institutional facilities for the mentally retarded. In this sense, deinstitutionalization is synonymous with depopulation. According to the President's Committee on Mental Retardation (1972, p. 31) at least one-third of those in institutions for the mentally retarded could, with proper training, become fully capable of community based living and productive employment.

As a process, deinstitutionalization encompasses four interrelated activities.

1) Preventing the admission of persons to institutional facilities by finding and developing alternative community methods of care and training;

2) Returning to the community all institutional residents who have been prepared through programs of habilitation and training to function adequately in appropriate local settings;

3) Establishing and maintaining a responsive residential environment which protects human and civil rights and which contributes to the expeditious return of the individual to normal community living whenever possible;

4) Promoting public acceptance of retarded persons as neighbors, employees and as citizens possessing civil and human rights.

Before proceeding further, it is important to distinguish deinstitutionalization from two other concepts: 'institutional reform' and 'decentralization.'

INSTITUTIONAL REFORM

Whereas deinstitutionalization refers to a reduction in the use of institutional type care, the term 'institutional reform' refers to an

up-grading and improvement of institutional care and training. "Institutional reform...involves a modification or improvement in attitudes, philosophies, policies, effective utilization of all available resources, and increased financing to provide adequate programs to motivate and assist individuals to reach their maximum level of functioning in the least restrictive environment possible." (PCMR, May, 1974, p. 4)

A potential for friction exists between the advocates of institutional reform and the advocates of deinstitutionalization. The basic sources of this conflict are the need to compete for scarse financial resources and the belief that resources flowing to an institution will not be available for community based services and visa versa. This competition may be especially strong in states where the agency responsible for funding community based services is different from the one responsible for funding institutional programs.

DECENTRALIZATION

Legislative proposals to deal with problems of institutions sometimes take the form of decentralization rather than deinstitutionalization. In other words, it is suggested that large state institutions be 'broken up' into more manageable units and dispersed throughout the state. An example might be a proposal to "decentralize" a 2,000-bed institution into four 500-bed residential units. The concept of decentralization may appeal to legislators who have used it successfully to solve problems in other public service areas. Essentially, the decentralization approach creates new 'mini-institutions' while the inherent problems of institutional care remain unsolved. When 500 or even 50 persons live in a facility it becomes an

institution regardless of its new name or location. Facilities of this size require rules, regulations, routine, visiting hours, loss of privacy, etc.--all of those institutional features which are barriers to the achievement or normalization and the least restrictive environment. After a large expenditure of money for smaller institutional facilities, states may discover that these, too, fall short of modern expectations and standards.

Contemporary professional opinion and parent groups generally consider large, state residential institutions to be an undesirable and inappropriate, if not harmful, environment for the mentally retarded. National Association for Retarded Citizens has recommended that all residential facilities consist of small living units, each of which is similar to a normal home environment. At its October, 1972, Annual Convention the NARC passed a resolution recommending that the establishment of these small living units take precedence over additional capital investments in existing or new large institutions.

THE DEINSTITUTIONALIZATION MOVEMENT

Over the past decade, several forces merged to generate the deinstitutionalization movement. In particular, the scandalous conditions found in many institutions spurred the search for alternatives. Such conditions were especially hard to accept when U.S. institutions were compared to successful community programs developed in the Scandinavian countries. In addition, advances in behavioral technology made it possible to train and educate retarded persons to levels previously considered unattainable. The concept of normalization and recent legal trends have been significant factors in generating the deinstitutionalization movement.

Normalization

The philosophy and principles of normalization have become pervasive and powerful motivating forces toward deinstitutionalization. A thorough understanding of deinstitutionalization for the mentally retarded requires an appreciation for and an understanding of normalization. Unfortunately, this brief report cannot do justice to this concept and its far reaching implications. The reader is, therefore, referred to works by Wolfensberger (1972), Nirje (1970), Zarfas (1970), Gunzberg (1970), and Bank-Mikkelsen (1969). An October, 1973, publication by the National Association for Retarded Citizens defines normalization as follows:

> The concept of helping the developmentally disabled persons to obtain an existence as close to the normal as possible, making available to them patterns and conditions of everyday life that are as close as possible to the norms and patterns of the mainstream of society. Specifically, the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible. (p. 72)

The term normative in the above definition can be equated with 'typical' or 'conventional.' This means, for example, that the retarded should, to the greatest extent possible, live in typical or conventional homes in ordinary neighborhoods and communities. Moreover, their work, recreation, clothing, transportation and other daily activities should be as conventional as possible. The principle of normalization rests on the assumption that adaptive or socially acceptable behaviors are learned because the learner has been given an opportunity to behave in conventional ways and has been rewarded for so doing. Institutional living provides few opportunities for learning behaviors which are adaptive or useful outside the institution. In fact, institutional placement can greatly reduce the chances of later adjustment in the community.

Below are other implications of the normalization principle:

> ...residential services, like all services generally need to be community-integrated and dispersed so that residents will intermingle with typical citizens in typical activities.
>
> residential units generally should be within easy walking distance to major community services such as shopping centers, public libraries, post offices, churches, schools, and recreational resources such as movie houses, bowling alleys, etc.. They should also be accessible to various transportation alternatives to facilitate entry in and contact from the community.
>
> ...services, and especially, residential services (need to) be small since neighborhoods and communities cannot absorb large numbers of (retarded) individuals.
>
> ...the normalization principle demands that as few central services as possible be provided as part of a residential unit. In other words, professional offices, educational space, treatment areas, etc., generally should not be in the same building that serves as a home. Residents should go to regular community resources and services, such as kindergarten, school, other education, shopping, most medical and professional services, movies, bowling, swimming and most other recreation. Only to the degree to which no alternatives are possible should such services be provided even on the same campus.
>
> residences should be no larger than is typical for the nuclear family in the community, e.g., six to eight members. (Wolfensberger, 1972, pp. 81-83)

It is important to note that the emphasis on community contact, integration and smallness are compatible with the need for specialization and continuity in a network of services. In fact, smallness facilitates the delivery of individualized service and creates the many options which make it possible for the retarded to secure the combination of services needed.

On occasions, a superficial explanation of normalization has misled the public and parents into believing that programs based on these principles would "make the retarded normal" or undo the condition of mental retardation. Whether these distorted explanations result from a misunderstanding of normalization or over-enthusiasm for innovative approaches, they are inexcusable and irresponsible.

Legal Action

In addition to the impact of the normalization principal on services to the mentally retarded, many of the recent court decisions have provided an impetus for deinstitutionalization. One of the most significant was the Alabama case of Wyatt vs. Stickney.

> The plaintiffs alleged that residents in the state's two mental hospitals and one institution for the retarded were receiving inadequate treatment or habilitation and that this violated their constitutional rights.
>
> ...In early 1972 Judge Frank Johnson declared habilitation services to be inadequate and issued detailed orders to improve the institutions, reduce institution populations and eventually return many mentally retarded residents to more appropriate community habilitative settings. (PCMR, 1974, pp. 9-10)

The principle of "least restrictive alternative" is also having a major impact. Under this principle, "...as a prerequisite to institutionalization of a mentally retarded individual, a state can be required to prove first that the individual cannot be habilitated in the community." (PCMR, 1974, p. 14)

Noteworthy is the fact that principles such as the 'right to treatment' and the 'least restrictive alternative' can also be applied to community based services. Unless these programs are adequately funded, adequately staffed and appropriate for the retarded, they too will be vulnerable to legal action similar to that which has been directed at institutions. For a review of other significant legal issues and court decisions the reader is referred to a 1975 PCMR publication entitled, Compendium of Law Suits Establishing the Legal Rights of Mentally Retarded Citizens.

The Issue of Cost

A fairly common argument in favor of deinstitutionalization has been the statement that community based services are less expensive than institutional care. From several perspectives the argument seems justified. For example, Conley (1973) has attempted cost-benefit analysis on various retardation services, including institutional care. From an economic viewpoint, he favors community based programs over institutional programs.

High quality community based programs are not, however, 'cheap.' In order to avoid a taxpayer 'backlash,' the public should not be led to believe that deinstitutionalization will reduce expenditures for mental retardation services. The ever increasing demand for community based services is certain to push program budget requests upward.

In considering deinstitutionalization the focus must be on 'what is best' rather than on 'what is cheapest.' This point was emphasized more than a hundred years ago. In 1857, Dr. Samuel G. Howe, the first superintendent of the first state institution for the mentally retarded in the United States offered the following assessment:

> The more I reflect upon the subject the more I see objections in principle and practice to asylums (institutions). What right have we to pack off the poor, the old, the blind into asylums. They are of us, our brothers, our sisters--they belong in families; they are deprived of the dearest relations of life in being put away in masses in asylums. Asylums generally are the offspring of a low order of feeling; their chief recommendation is that they do cheaply what we ought to think only of doing well. (Schwartz, 1956)

A few things have changed over the past 100 years; institutional care is no longer cheap. Moreover we now have the knowledge and the experience necessary to create suitable alternatives for most of the retarded.

BARRIERS TO DEINSTITUTIONALIZATION

Despite the clear national trend toward deinstitutionalization within the field of mental retardation, the movement faces a number of obstacles. An overview of deinstitutionalization, even a brief one, must also focus on sources of opposition to the goal and process of deinstitutionalization.

Resistance by Parents

Some parents of institutionalized persons have mixed or negative reactions to deinstitutionalization. Typically, parents who place their child in an institution experience great personal anguish and conflict over their decision. The placement is made after professional consultation and with the belief that it is the 'best thing' or the 'only thing' to do. Once their child is in the institution, parents naturally feel threatened by talk of depopulation and community placements. The possibility of their child leaving the institution often reactivates old personal conflicts. They may fear that they will again be burdened with the care of their handicapped child or that their child will be placed in an inappropriate community facility where he is subject to exploitation or abuse. Thus, their fears are quite understandable.

Parents of retarded persons in the community may also feel threatened by deinstitutionalization. Even though they have not placed their child in an institutional setting, the existence of such a facility provides them with a sense of security. They know that the institution is there, if and when they need it.

In order to allay parental fears, persons concerned with deinstitutionalization must work closely with parents and parent groups such as Chapters

of the Association of Retarded Citizens. Parents need to be informed of community based alternatives and assured that these programs will provide equal or better care than that provided by institutions. The existence of successful and stable programs in the community is, of course, a prerequisite to providing this assurance.

Community Resistance

For many years, the National Association for Retarded Citizens and other organizations have worked diligently to overcome myths and misinformation about the retarded. Despite these efforts, many individuals and communities still fear and reject the mentally retarded, especially those who have been stigmatized by prior institutional placement. Cherington (1974) has noted that:

> ...most communities will accept a retarded person who manages marginally unless he is labelled retarded, at which point many indeed will reject him. Experience with deinstitutionalization efforts indicates that some communities tend to reject retarded people who are labelled as such. The community sees them as strangers from another world.
>
> On the other hand, retarded people who are enabled to grow and develop naturally within their communities are seen as legitimate members, and are not so easily rejected. Between outright rejection and overt acceptance, too, are many ways of rejecting retarded people--subtle, seemingly benevalant ways. Many of the special restrictions placed by governments on the locations and types of residences which retarded people may occupy or the creation of special recreation hours at community facilities are examples. (p. 3)

It is interesting to note that some resistance to community based programs comes from the fear that living arrangements such as group homes for the retarded will decrease neighborhood property values. In many ways, the retarded face discrimination similar to that experienced by Blacks and other

minorities. Community education is necessary to overcome resistance. Community leaders must be helped to understand the need for community based programs and the reasons behind deinstitutionalization. Experience in Nebraska has demonstrated that extensive programs of public education can overcome many fears and sources of resistance.

City and county governments may resist deinstitutionalization because they fear it will result in higher expenditures of education, public health and public welfare. In one state, for example, foster homes payments are 50% county funded. Thus, each person transferred from a state institution to a community foster home requires an additional expenditure by the county.

Local school districts are sometimes reluctant to admit formerly institutionalized retarded into their classes. They often feel that these retarded persons are inappropriate candidates for special education and/or that the required programs and staff will be costly.

Resistance by Economic Interests

A large state institution with hundreds of state employees is an obvious economic asset to its host community. Thus, business interests are likely to react negatively to any deinstitutionalization proposal that may have an adverse affect upon the local economy. Special problems exist in rural states where institutions are located in small towns and are central to the economy. A significant reduction in institutional based programs will have a definite and unavoidable impact on such communities. Special state and federal assistance may be needed to counterbalance such economic dislocations.

Resistance by Institutional Employees and Unions

Increasingly, purchase of service arrangements are used to create and operate the community based services which make deinstitutionalization possible. Thus, the resulting expansion of human service employment is more likely to occur within private non profit or profit making agencies than within state government. State institutional employees wishing to work in these community programs find that they must change employers and possibly loose certain employment benefits (retirement, union membership, etc.). This reality may generate opposition to community based programs that are state funded but not state operated.

Individual employees and employee unions may oppose deinstitutionalization because they fear it will eliminate jobs or restrict advancement opportunities within the institution. This concern is most common among non professional staff who have few other employment opportunities. In reality, staff cutbacks in institutions for the mentally retarded have been rare. In many cases, the demand for high quality services which are accompanied by the deinstitutionalization movement leads to an expansion of institutional staffing. For example, in 1975 Nebraska's Beatrice State Home had more institutional employees than it had in 1967 when its resident population was twice as large.

Labor unions have become a formidable foe to those interested in deinstitutionalization. A recent 44-page publication prepared by Santiestevan (1975) for the American Federation of State, County and Municipal Employees (AFSCME) makes a strong attack on deinstitutionalization.

> The philosophy of deinstitutionalization has provided an excuse to cut back on even these meager services in order to save money

> for local governments and make money for private entrepeneurs. The incentives have come in the form of federal money available only to private facilities and crude inducements...to dump patients out of mental hospitals and into the streets. (p. 40)
>
> ...(institutional) health workers have had too many negative experiences with deinstitutionalization as a shell game for budget cuts, layoffs, and profiteering not to be skeptical of the most impressive sounding plans. (p. 34)

As reasons for its opposition, the AFSCME cites numerous examples of inappropriate community placements, the overuse of nursing homes and a lack of community based alternatives. Unfortunately, successful deinstitutionalization efforts are not mentioned and the AFSCME publication does not clearly distinguish between institutions for the mentally ill, the mentally retarded and juveniles. It does not discuss the principle of normalization and legal concepts such as the 'least restrictive environment' which have generated the deinstitutionalization movement. In its concluding pages, the AFSCME publication formulates three recommendations:

> 1) Public funds should only by used for non-profit and public facilities.
>
> 2) There should be a moratorium on administrative discharges of mental patients from state institutions until there has been planning through a public process for a network of community services.
>
> 3) State mental institutions with their proven ability to provide long-term intensive care, must continue to play an important role in any (service) system of the future. (pp. 41-42)

Fear of Failure

Some resistance to deinstitutionalization stems from concern over whether new community based alternatives will be 'successful'. In view of the fact that deplorable conditions have been found in some community

programs, the concern is a valid one. On the other hand, there are numerous examples of successful programs which are superior to institutions and it can be argued that all community programs should not be opposed because some have been failures. Rather, rigorous performance standards and monitoring should be used to maintain quality community programs. Wolfensberger (1972) has made an interesting comment on this issue:

> We have behind us 50 years of failure, and we can scarcely do worse than we have with our past patterns [institutions]. Some people now say that we should not try new patterns because they are unproven. But in actuality, ...the worst that can happen is that we do as badly as in the past while the best that can happen is a breakthrough to a new age. (p. 9)

WHAT IS AN INSTITUTION?

Not infrequently, discussions of deinstitutionalization begin and end with a focus on problems and issues related to the expansion of community based living arrangements and supporting services for the mentally retarded. The existence of alternatives such as foster homes, group homes, hostels, sheltered workshops, developmental centers, etc. are essential to successful deinstitutionalization. Without community based alternatives, deinstitutionalization is a moot goal.

It is, however, important to recognize that a critical appraisal of deinstitutionalization and realistic planning for deinstitutionalization must first grapple with the question, "What is an institution?" Without a clear answer to this question advocates of deinstitutionalization entertain the risk of simply relocating institutional care rather than reducing it.

The definition offered by Wolfensberger (1972) appears to capture the essence of an institution:

> ...term institution refers to a deindividualizing residence in which persons are congregated in numbers distinctly larger than might be found in a large family; in which they are highly regimented; in which the physical or social environment aims at a low common denominator; and in which all or most of the transactions of daily life are carried on under one roof, or one campus, or in a largely segregated fashion. (pp. 80-81)

Large size, insulation from the community, loss of individuality and privacy, routine caused by rotating shifts and the provision of all services (meals, training, recreation, sleeping arrangements, treatment, etc.) within the same facility are among the characteristics which distinguish an institution from community based living arrangements (e.g., small group homes, hostels, foster homes, etc.) and services (e.g., sheltered workshops, work stations, activity centers, day care, etc.).

Unless program planners, professionals and parent groups are diligent and attentive, community residential programs may evolve into "mini-institutions." In some areas, the inappropriate use of nursing homes and the establishment of large group homes has done little to effect deinstitutionalization. The result has been relocation rather than deinstitutionalization. The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded have recognized this danger:

> While the Association advocates without reservation the rights of the retarded to live in the least restrictive environment and to enjoy fully the benefits of a free and open society whenever possible, it does express concern over the manner in which this goal is being realized. First, the quality of community programs and services being offered to the mentally retarded and other developmentally disabled persons in many parts of the country is inadequate. All too often, "community back wards" and "closeting" are being substituted for institutional "warehousing." Neither community nor residential back wards or "closeting" are justified; the rights of the retarded must be respected wherever they reside. In essence, the Association calls attention to the need not only

> for continued upgrading of residential facilities toward becoming decent, viable, and responsive environments reflecting normalization for those who, for some time, will require specialized residential care, but also calls for a greater interest in quality control for developing community programs. (PCMR, May, 1974, p. 2)

Some efforts to deinstitutionalize have resulted in the inappropriate placement of the retarded in facilities for the mentally ill or the aged even though these three groups are quite different and each requires a unique approach to treatment, training and care. Most professionals consider this to be an unacceptable practice. This practice is also opposed by the National Association for Retarded Citizens.

> Without appropriate recognition of the specific and unique needs that retarded persons have according to their degree of retardation, and their life needs, additional problems can be imposed in the way of competition, frustration, abuse, failures, being taken advantage of by other residents, and a general lack of program aimed at helping the retarded individual reach and achieve his maximum potential. (October, 1968, pp. 10-11)

This inappropriate 'mixing' is usually the result of insufficient community resources or the overuse of nursing home facilities.

Without proper monitoring and standards, even foster homes can become little more than miniature institutions. Regimentation, isolation from the community, and dehumanizing conditions are not unique to institutions. For example, a study by Murphy, Rennee, and Luchins (1972) concluded that:

> ...those who think foster home placements enables a patient to escape the disadvantages of an institutional life are mistaken. Foster homes can be as institutionalized as hospitals, while lacking the compensatory advantages some hospitals might possess. (p. 14)

Careful personnel selection, adequate levels of funding, training for foster parents and group home personnel, rigorous licensing procedures, client advocacy and follow-along services can prevent dehumanizing conditions from developing in community programs.

COMPREHENSIVE SERVICE SYSTEM

To a very great extent, deinstitutionalization is dependent upon the availability of community based alternatives to institutional care. Since few, if any, communities or areas have adequate resources for the retarded, planning for deinstitutionalization must focus on the creation of a comprehensive community based service system. The following definitions may help to clarify this concept.

> Service System - This concept encompasses all the physical units and other resources required to provide assistance (service) to people. These include buildings, equipment, staff, funds, etc. An important element in the concept of a "system" is the existence of strong "linkages" between all these service components. Without these important linkages, the system is merely a collection of separate parts and resources.
>
> Comprehensive - In order to be "comprehensive" a "service system" must meet the needs of all different age groups that require service, cope with problems of all different degrees of disability, include different socio-economic backgrounds, and be available when needed and where needed by the individual or family.
>
> Community Based - Means located in towns, cities and regions where people live and in a manner which blends in with the surrounding community. Elements of local control and management may also be included in this concept. (National Institute of Mental Retardation, 1974, pp. 64-65)

According to Mayeda (1971) several local and state characteristics must be considered in the development of a service system. These are: (1) land area, (2) population, (3) economics, (4) professional resources, (5) organizational resources, (6) consumer or client characteristics and (7) transportation. The system should provide a 'continuum of care' and a 'fixed point of referral,' two features that are emphasized in nearly every study of service for the mentally retarded. Case management or follow along services must be at the hub of the service system so as to insure that services are available, accessable and appropriate for the consumer. Planning and administrative structures should encourage coordination, accountability,

quality control, citizen participation and client advocacy.

Scheerenberger (1974) has identified five elements essential for successful deinstitutionalization: (1) a local or regional board with statutory authority to plan, implement and coordinate programs, (2) an independent standard-setting and monitoring agency which is separate from the local or regional boards, (3) quality back-up services and technical assistance which are accessable to boards and agencies, (4) adequate financial support for both residential and community based programs, and (5) a strong advocacy program.

Scheerenberger has emphasized that the local or regional boards be legally accountable for the service system as a whole and for each individual client. They should be policy-making boards rather than simply advisory groups. (Legislation was recently passed in Wisconsin which created community boards with full authority, responsibility and accountability for the provision of the 16 basic developmental disabilities services--all state funds except those for public schools and residential facilities are channeled through these local boards.) Standard setting and monitoring agencies or boards must have authority to terminate the funding of inadequate or unresponsive programs. Without such authority, it is extremely difficult to create a comprehensive network of relevant and quality services.

Adequate follow along and case management services are essential to successful deinstitutionalization. A recent study of five state programs for the retarded revealed that:

> A fairly uniform failing among states is their lack of detailed scrutiny of the daily cycle of care provided to a mentally retarded individual once that person has been placed in a community facility. ...A sometimes valid complaint of institutional workers is the loss in care given a person when that person transfers from a state facility to a community residence. (Mayeda, 1971, p. 11)

Like all citizens, retarded individuals have different abilities, interests, values and needs. Each is a unique individual, each possesses a unique potential for development. Thus, services, opportunities and responsibilities must be individualized and flexible. Each retarded person requires a changeable combination of services throughout his life span. No one service or any one combination of services is appropriate for all retarded persons. Thus, services for the retarded must be planned and developed as a system composed of a wide array of components. All parts of this system are interrelated and interdependent. A simple example may serve to illustrate this system perspective.

> John is 19 years old. After many years in an institution for the retarded he is about to be placed in a community group home. In addition to a place to live he needs a sheltered workshop where he can learn basic work skills. In such a program he will make some money but not enough to live on. Therefore, he needs financial assistance such as S.S.I. John enjoyed the bowling program at the institution. He needs similar recreation in the community. He also needs transportation to get back and forth to work and recreation. His years in the institution have not provided much opportunity to learn to handle money, care for his clothing or to use public transportation. Thus he needs training in personal care and 'survival' skills. He also needs additional education in reading and arithmetic. Because moving into the community will require many personal adjustments he may need counseling. He also needs ongoing medical and dental care. By the time John is 22 he may have acquired skills which make it possible for him to leave the workshop and move on to a sheltered work station in a local factory. At that point he may require less supervision and be ready for a different type of group home or for a semi-independent living arrangement. As John moves within the total service system, adequate follow along and advocacy is needed to insure that his programs are appropriate, coordinated and in keeping with his human and civil rights. This follow along must be coupled with an ongoing evaluation of John's progress, needs and desires.

Checks and balances must exist within the service delivery system. Advocacy programs, especially legal advocacy, are essential. Advocates

need to monitor local boards, agency programs and the services received by individual clients. Active parent groups such as chapters of the Association for Retarded Citizens, are an invaluable advocacy resource.

Gelman (1974) has formulated the following principles that should guide the creation and operation of a comprehensive service system:

> The system should identify and register needs of persons. The person in need should be the focal point of the system; the initial and continual evaluation and assessment of needs would allow for the appropriate match of the individual to an array of services.
>
> The continuum of services should meet these identified needs. A sufficient range of service components must exist to meet the variety of known needs. Services should be accessible to persons of all ages and all degrees of disability. Services must be comprehensive and appropriate to the needs of individuals.... This may entail developing different forms and modes of service delivery, including outreach, mobile teams, resource centers, and new funding sources.
>
> The continuum of services should be provided where possible through generic service systems, to which parents and clients have guaranteed access. No specialized service should be developed to meet the identified needs of an individual when existing agencies could address such needs... The system should stress the importance of the family in planning and decision making. Such an effort will have to view parents as potential resources rather than as obstacles to be overcome.
>
> Coordinating mechanisms should exist among agencies and service systems ensuring the goals of the individualized habilitation plan. All services, generic and specialized, must be linked together to facilitate coordination in line with the specified needs of the individual...
>
> Service settings must reflect geographic dispersal at the community, area, and regional levels. The component parts of the service system should be located at levels where clients can obtain them readily. Services should be combined in ways which will ease interdisciplinary approaches to common and special needs. Some services should be highly mobile so that distant clients can use them.

Service settings should strive to integrate the individual into the mainstream of community life. The service system must strive to create new and more appropriate living patterns for mentally retarded citizens, including participation in the activities of the community appropriate to people of the same age. Such social opportunities pertain to both children and adults.

A normal range of options should be available for parents and clients among an array of services. This includes the right to enter and leave the system as the need occurs. This range of options refers to the continuum of care previously discussed. Individuals may move into or out of the service system as needs arise. Access to and egress from the system must be guaranteed. The system must recognize that some individuals may need combinations of services for a long time, while the majority may "only" require specific services for a relatively short time.

Services should be instituted at the appropriate time. Appropriately timed interventions lead to an improved level of functioning. The effectiveness of late interventions is minimal. Age obviously is a crucial factor in this process. Age is important not only regarding the initiation of a service but also regarding the kind and duration of service.

The human and civil rights of all persons should continuously be observed and served, including appropriate habilitation within the least restrictive setting, regardless of the severity or combination of disabilities. The various recent statements regarding rights and the impact of class action proceedings have opened many new avenues for mentally retarded persons...

Record systems should be designed and maintained which facilitate program efficiency and effective service analysis. Record systems must maintain the continuity of individual program planning, document a client's progress, store reliable information, and assess the program's effectiveness. The records system must guarantee appropriate confidentiality.

Program evaluation should be integral to all service systems and reflect the involvement of consumers, system staffs, and the public. The input and involvement of persons not directly involved in providing service is crucial. A provider of a service is not an impartial and objective evaluator of his own interventions. The agency and the service system of which it is a part must have built in and ongoing mechanisms for monitoring the quality of its operations.

All service systems should be accredited or have plans for achieving accreditation within three years. This goal will become a reality soon. Mechanisms now exist for all systems, both residential and non-residential, to achieve the standards set forth by the Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals.

To assure effective implementation and functioning of the service system, qualified specialists should hold positions of leadership in the system. Without this prerequisite, effectively meeting the diverse needs of mentally retarded individuals becomes an exercise in futility.

Mechanisms should be established between Education/Training Programs and the service delivery systems to assure the continuous availability of enough appropriately trained personnel to meet the goals of the service system. The relationship between education and training facilities (i.e., colleges, universities, University Affiliated Facilities) must be refined to meet the needs of the service systems. Such an arrangement can lead to new methods which may more appropriately meet the needs of mentally retarded persons.

Laws should be recodified to facilitate the development of services and facilities to fulfill the goals of the service system. Legislation has received a great deal of attention in recent years because of the perception that new legislation can answer a long standing problem. The need very clearly is one for good, adequate, and implementable legislation, not legislation which creates additional confusion.

Prevention should be an integral component of the service system, and measures should be planned and implemented to reduce the incidence and severity of mental retardation... Preventive services must reflect present knowledge and effectively use private and public resources. The potentials that exist through new medical advances (e.g., amniocentesis) and new screening techniques for PKU and sickle cell anemia must be continued. Prevention must be an ongoing part of all components of the service system. In many instances appropriately timed intervention may prevent the need for other services.

An effective means for educating the public and generating public awareness and support should be implemented. The need for an adequate and appropriate program of education and awareness must be conducted on several levels, i.e., professionals, the public, and the legislature. (pp. 92-95)

DEVELOPMENTAL MODEL

A Comprehensive Service System for the mentally retarded should adhere to the developmental model and principles of normalization. (Menolascino and Pearson, 1974) In the past, retardation programs and services have been guided by what is often termed 'medical model.' This has resulted in an overemphasis on pathology and caused many persons, including many professionals, to view mental retardation as a static and rather hopeless condition. It has placed the emphasis on limitations rather than on potential. According to the developmental model "...the mentally retarded are capable of development, growth and learning. Each individual has potentials for some progress, no matter how severely impaired." (Roos, 1969, p. 7)

The Survey Research Center of the University of Michigan has reported rather striking differences between programs guided by the 'medical model' and those guided by the 'developmental model.' The President's Committee on Mental Retardation (1972) summarized the study as follows:

> Those facilities with an educational treatment technology, almost without exception, provided higher levels of care, more balanced programs, and more equalitarian rendering of services to recent versus long-term residents than other facilities did.
>
> Facilities with a medical or psychiatric treatment technology had many residents who actually deserved educational and other therapeutic service, but who received far less than their share of these.
>
> Residents at medically oriented institutions, when matched with those of equal functioning at educational facilities, nevertheless were provided far fewer educational, social, vocational and even certain medical-nursing services than their fellow residents at educational facilities.
>
> These and other structurally-based differences existed despite about equal financial and other resources between the two kinds of facilities.

COMMUNITY EDUCATION

As a prerequisite for securing long term public and legislative support for deinstitutionalization and the development of community based programs, citizens and elected officials must understand and accept the rationale for a policy of deinstitutionalization. Like other public policies, it must win acceptance at the state level. Moreover, deinstitutionalization must find acceptance at the community level. Community programs based on normalization are unworkable in an environment hostile to the retarded or staunchly opposed to the idea of formerly institutionalized retarded attending community schools, living in their neighborhood, using public transportation, using community recreation facilities, etc.

INVOLVEMENT OF PARENTS

Parents of the retarded and parent organizations play a key role in stimulating the development of community based programs. They also do much to shape community attitudes toward the retarded. An organized parent lobby can usually exert significantly more influence on elected officials than can professionals and program planners. Attempts to develop programs or effect deinstitutionalization without parent involvement is both foolhardy and shortsighted.

Planning for deinstitutionalization should involve a cross-section of parents (e.g., Association of Retarded Citizens members and nonmembers, parents of the institutionalized retarded and parents of retarded in the community). Their involvement (1) lends credibility and legitimacy to the planning process, (2) serves to lessen community resistance to deinstitutionalization, and (3) provides a set of 'checks and balances' which prevent governmental units from

running roughshod over sensitive family issues and values. Parent advisory groups should be established to monitor deinstitutionalization efforts. In order to secure input from low income parents, state and community planning bodies should provide transportation and per diems if needed.

Because strong parent groups are so valuable and effective, governmental units should search for acceptable ways of facilitating (but not controlling) their development and expansion. This is especially important in rural areas where parent organizations are small in size and tend to be organizationally weak.

INVOLVEMENT OF THE RETARDED

Retarded persons, those in the institution and those in the community, should be involved in planning for deinstitutionalization. Their insights, experiences and recommendations can be invaluable to those designing and operating community based programs. For example, in 1970 fifty retarded delegates to the 'National Conference of Retarded Young Adults' in Malmö, Sweden, prepared a set of recommendations related to programs in Sweden. (Wolfensberger, 1972) Similar conferences at the state and community level should be utilized in the United States. Retarded persons should also serve on advisory and policy making boards.

The retarded person can be extremely effective in legislative hearings. Recently, several retarded adults, all former institutional residents, testified before 1975 Montana Legislative committees. What they had to say had more impact than testimony offered by parents and professionals. In the age of the consumer more attention should be given to the consumer of mental retardation services.

TYPES OF SERVICE WITHIN A COMPREHENSIVE SYSTEM

A comprehensive system of community based services which will both prevent institutionalization and permit institutionalized persons to return to their communities must include five broad types of service: (1) Family Support Services; (2) Child Development Services; (3) Residential Services; (4) Vocational Services; and (5) Central Support Services.

Family Support Services

Numerous studies indicate many retarded persons are institutionalized or placed out of their own home because of a family crisis, not because of the retarded person's behavior. Family support services can often prevent such placements. Examples include genetic counseling, assessment and diagnosis, individual and family counseling, crisis assistance, respite care, visiting homemakers, in home therapy, parent/child training, recreation, transportation, citizen advocacy, lending library, information and referral, financial subsidy, follow along, pilot parent programs, ARC, etc.

Child Development Services

Child development services fall into two areas: (1) developmental programs for preschool age children and children with exceptional disabilities; and (2) public school education.

> Child development services must be recognized as among the most important of all services because through early intervention with intensive programming, handicapped children may overcome many of the effects of their handicapping condition. The early development of basic skills give the handicapped child a crucial head start which ultimately can make a difference between a life as a handicapped person and a life as a competent citizen. Researchers and programmers have shown how spectacular gains in measurable

> intelligence and ability can be obtained by exposing handicapped children to consistent, intensive and stimulating programs. (National Institute on Mental Retardation, 1974, p. 70)

Examples of child development services include infant stimulation, training, day care, school preparation, behavior shaping, maintainance of life, and developmental maximation. School systems are often capable of providing other services such as academic skill training, language development, life skills training, physical education, recreation, vocational preparation, career counseling, cultural enrichment, remediation for special difficulties, etc.

Residential Services

A wide range of residential options need to be available for those individuals who cannot remain in their own homes even with the assistance of family support services or who have reached an age where it becomes more "normative" to leave ones family home. To the greatest extent possible, residential services should approximate the typical living situation for a given age group. Examples include adoptive homes, foster homes, boarding homes, group homes and apartments. In addition, a continuum of residential options should include an array of living arrangements which provide back-up or supplemental services to those mentioned above. According to the National Institute on Mental Retardation (1974) these might include:

> Life support or developmental maximation--to serve children/adults with profound degrees of mental retardation and multiple handicaps, where intensive medical care is also required;
>
> Infant nursery and developmental programs--for retarded infants and children below school age;

Child development hostels--for children within the age range 3 to 18 years who require a typical family-type situation with older and younger children;

Intensive behavior management units--a temporary residence for severely handicapped persons over 6 years of age;

Structured correctional group homes--for difficult to manage and anti-social persons;

Training hostels (type 1)--a short-term service for retarded individuals over 16 years, to prepare for self-sufficient living;

Training hostels (type 2)--a long-term residence for more severely retarded individuals;

Training hostels (type 3)--for retarded adults who are able to function with minimal supervision;

Apartments (type 1)--maximum independence, (type 2)--co-residence/staff apartment, (type 3)--apartment cluster;

Crisis assistance homes--for temporary placement of children and adults where family circumstances make the removal of the handicapped person necessary;

Habit shaping unit--a specialized short-term residence for those persons who do not fit into more normative living arrangements and require extensive habit shaping and socialization.

Vocational Services

Work is an important part of adult life and an individual's personal identity. Vocational services, coupled with various support services, can assist retarded persons to become more independent and productive.

> The goals of...vocational services are two-fold: (A) to provide every individual, no matter how handicapped, with the opportunity to become totally or partially self-supporting through vocational choice and career; (B) to develop vocational opportunities so each handicapped individual is assured of a reasonable chance to participate in meaningful and self-enhancing work... (National Institute on Mental Retardation, 1974, p. 74)

The range of vocational options should include sheltered work, sheltered industry, on-the-job training, work stations in commerce and industry, trades

training and employment, part time employment, full time employment, self employment, etc. A variety of other services should support or complement vocational services. These include selection and assessment, recruitment, prevocational training, vocational exploration, vocational evaluation, work adjustment, skill training, placement, follow along, on site orientation, job stabilization, retraining, etc.

Central Support Services

A comprehensive service system consisting of dozens of different service units scattered throughout a region requires a sound organizational and administrative structure. Functions of Central Support Services include administration, fiscal control, staff development, public relations, public education, research, and program evaluation.

COMPETITION FOR SERVICE

Of the several million retarded in the U.S. about 200,000 reside in institutions for the retarded. Most of the retarded do not and will not need institutional type care. They do, however, need the services provided by community based programs. Thus, two groups of retarded need community based services: (1) those living in the community and (2) those who could leave the institution if appropriate community based services were available. In many ways, these two groups must compete, directly or indirectly, for scarce community services.

As background for considering the issues of demand and competition, it is important to recognize that pressure from parents of the noninstitutionalized retarded has been a key factor in the establishment of community

based programs. Few viable community programs have been created without their support and influence. In general, parent groups and professionals have been more active in the creation of community services for the non-institutionalized retarded than for those who are in state institutions.

Since the demand for community based services usually exceeds the supply, a public policy of institutional depopulation can create an unwelcome demand on existing services. In some cases, the added demand forces providers of service to choose between the retarded already in the community and those coming out of institutions. Since parents and community professionals often serve as 'advocates' for the noninstitutionalized retarded, local programs may be more responsive to the needs of the retarded in the community than to the needs of those coming out of institutions. The institutionalized retarded seldom have as many 'advocates' willing to fight or bargain for services. Therefore, creation of additional community based services does not, in and of itself, insure that the institutionalized retarded can be placed in the community.

An awareness of this issue has sometimes prompted the recommendation that a 'quota system' be used to insure that additional state funding for the expansion of community based services will, in fact, result in depopulation of state institutions. In effect, the approach forces community based programs to provide services to the institutionalized retarded, thereby facilitating placement out of the institution. This approach is usually resisted by community programs. It is viewed as being too rigid and administratively complex. They also fear that quota systems will result in inappropriate community placements. While there is no completely satisfactory solution to this problem, simple informal agreements between institutions

and community programs have been used successfully. This solution is dependent upon a good working relationship between institutional staff and community program personnel and a philosophical commitment to depopulation by parents and professionals in the community.

MODELS OF DEINSTITUTIONALIZATION

States or communities interested in developing alternatives to institutional care usually seek policy and program information from areas which have had experience in the establishment of workable models. This is a very logical and common sense procedure. There are, however, inherent problems in 'borrowing' a model which was developed within a different social, economic and political context. A model which works well in one area may not work elsewhere. Few, if any, programs or approaches evolve without many compromises and changes from the ideal to the feasible. Thus, the indiscriminate borrowing of a model or an approach may give rise to unexpected problems.

This also applies to the borrowing of change tactics and strategies used in other states and areas. It is, of course, helpful to know about change efforts in other areas but it is much more important to possess a thorough understanding of ones own state and especially differences among communities. It is a mistake to assume that an approach which created desirable change in one community or area will be equally successful elsewhere. Factors such as charismatic leadership, strategic timing, political climate, favorable publicity, and readiness for change may converge to generate significant movement toward the development of institutional

alternatives. Such factors cannot, however, be created or replicated at will. A degree of opportunism and serendipity is involved in all planned social change.

In discussing the politics of community action related to the development of community services for the mentally retarded, Holland (1974) has noted that:

> Changes will come arduously and slowly, but these situations are not impervious to appropriate influence carefully applied. Strategies for mobilizing the needed services are based upon careful analysis of the social forces to which the agencies respond and the skillful accumulation and application of such influences to appropriate points in the target agencies. Social and political resources can induce or constrain decision-making groups to allocate the services needed by retarded persons. Such carefully planned and executed advocacy efforts can result in marked changes in the availability, accessibility, and effectiveness of human services. (p. 181)

Unfortunately, there are no "ten easy steps toward deinstitutionalization." Rather, models, strategies and tactics must be individualized to local circumstances. Deinstitutionalization does not occur in a vacuum. A whole host of economic, political, cultural, and social factors affect what can or cannot be done at a particular point in time in a particular area. Because successful deinstitutionalization is so dependent upon public support for new programs and community acceptance of the mentally retarded, rigid or ill timed plans imposed upon a state, region or community tend to generate more resistance than results.

EXAMPLES OF DEINSTITUTIONALIZATION EFFORTS

Approaches to deinstitutionalization and the development of community based programs vary from state to state. Obviously, political and economic realities shape strategies, administrative structures and funding patterns. As previously indicated, an approach which works in one area is not necessarily workable in another. A brief examination of a few approaches does, however, serve to illustrate similarities and differences.

Connecticut

In the late 1950's crowded institutions and long waiting lists for institutional care prompted the Connecticut Association for Retarded Citizens and other interested persons to work toward a solution to the problem. An Office of Mental Retardation was established in 1958. Subsequently, the State was divided into 12 regions. Connecticut was one of the first states to regionalize its services for the mentally retarded. Each regional service center is state funded and state operated.

> Most regional centers provide an array of services, including case services, diagnosis, evaluation, functional education, respite care, short-term and long-term residential care, vocational training, sheltered workshops and more.
>
> Regionalization has been the greatest deterrent to institutionalization in Connecticut by providing the supportive and program services necessary to sustain most mentally retarded persons within their home communities. Regional services available to families are usually within 20 minutes travel time from home. (Connecticut Office of Mental Retardation, Oct., 1974, p. 9)

Significant changes have occurred during the past 10 years at Connecticut's two institutions. The Mansfield Training School is one of these. It has adopted a 'community orientation.'

> We do anything we can to close the gap between the community and our residents...The clothing store and the beauty parlor and the snack bar and the teen club...are not just for the purpose of making the lives of Mansfield residents more pleasant and more normal. They are also preparation for the life that many will be living in the community.
>
> Whenever possible, the children go to local public schools...Many of the retarded adults hold jobs in neighboring industries.
>
> Residents take train rides into nearby cities to visit museums, zoos, parks, fire departments, airports--whatever the community offers that will add to their experience. (P.C.M.R., 1973, p. 39)

Between about 1967 and 1974 the resident population at Mansfield has been reduced by about one-third.

Connecticut now utilizes a 'contract for service system.' All admissions to the Office of Mental Retardation Program, whether to a regional center or to a training school, require that a contract for service be promulgated on each person entering the program.

> The contract for service, which is negotiated with the client and the family or his guardian, requires that specific program objectives be outlined and that a program plan be developed to meet these objectives within a designated period of time. In every case possible, the active involvement of the family or the client's guardian is included as part of the contract substance to attain the program objective. The contractual system has eliminated the majority of long-term admission decisions and substituted therefore residential care plans for shorter periods of time with the focus on returning the person to the community as soon as feasible. (Thorne, 1973, p. 2)

In addition to the state operated regional centers and residential facilities, Connecticut utilizes a grant-in-aid system to provide financial assistance for the development of community-based programs by the private sector.

> These programs include preschool activity programs, day care, vocational and sheltered workshop programs, social recreational programs and diagnostic services. All of the programs are non-profit enterprises receiving, aside from grant in-aid funds,

> support through United Funds, donations, fund drives, and profits from sheltered workshop contracts.
>
> The Connecticut statutes specify responsibility to the Office of Mental Retardation to administer the grant-in-aid program and to develop certain standards of operation to ensure the adequacy of the services provided. (Thorne, 1973, p. 3)

Connecticut has also instituted a computerized information system which connects the 13 Regional Centers, the training schools and the Office of Mental Retardation. This system provides comprehensive information,

> ...on many program and client elements that are essential to planning, developing and supporting a system of services designed to keep people from having to enter institutions and to enable persons presently residing in institutions to return to the community. (Thorne, 1973, p. 2)

Recently the Office of Mental Retardation completed a 5-10 year service improvement plan titled Project Challenge. Major goals include the reduction in size of the two training schools and the enhancement of residential care systems which provide short-term and respite care. To the greatest extent possible services will be moved out of the institutions and into the community.

Nebraska

In 1967 Nebraska could be described as "...one of the least progressive of the United States as regards provision and funding for mental retardation services." (Wolfensberger, 1972, p. 95) During that same year the state's average daily institutional population was 2300. By the early 1970's Nebraska had become a national pace setter in the development of innovative and quality community based programs. By 1975 its institutional population had dropped by more than 50% to less than 1100. A state plan calls for

further reduction to 850. A waiting list for institutional care has not existed since 1972.

This remarkable record and near revolution in the delivery of services to the mentally retarded has been termed the 'Nebraska phenomenon.' Nebraska's experience is especially impressive when one considers that it is essentially a rural state and conservative, both fiscally and culturally. It is not a State that has a reputation for 'jumping on the bandwagon' or impulsivity. One can only deduce that a great many Nebraska citizens and elected officials concluded that alternatives to institutional care for the mentally retarded were desirable, necessary and economically feasible.

The Nebraska phenomenon began with a 1967-68 study of the State's institution. The study was requested by the Nebraska State Association for Retarded Children and was a response to overcrowded conditions and a concern over the quality of care provided at the institution. The study was conducted by a citizens' committee appointed by the Governor.

> During the course of this study, the Committee concluded that the problems of the Beatrice State Home were not soluable except in the context of a radically new approach to services to the retarded generally. In consequence, the Committee then drew up what was, in effect an entirely new state plan... (Wolfensberger and Menolascino, 1970, p. 20)

An important feature of the study process was Governor Tiemann's willingness and eagerness for the Committee to have access to all institution wards, personnel and materials such as budgets. Nothing was hidden from the Committee. According to Wolfensberger and Menolascino (1970, p. 20)

> The report evoked much controversy...it also evoked massive publicity and extensive support from all levels of social organizations: from citizens on the street, to county commissioners, state legislators, and the governor himself.

The new plan formulated by the Committee was a break with the past. It laid the groundwork for the rapid change that followed.

> These committee members, infused with the spirit of the human dignity movement, the developmental model, and the normalization principle, altered the state's approach to its retarded citizens. Parents and professionals joined forces to write a plan for a system of community based services which would meet the needs of all retarded persons within the normalization concept. (ENCOR, Historical Perspectives, p. 1)

A massive public education campaign was waged by the Committee and parent groups in 1968. By 1969 the Nebraska legislature had passed fourteen bills relevant to the new State Plan, one of which established six regions in the state responsible for service delivery. One of these, L.B. 855, contained the following:

> It is hereby declared to be the public policy of the State of Nebraska that a pattern of facilities, programs and services should be available to meet the needs of each mentally retarded person so that a mentally retarded person may have access to facilities, programs and services best suited to them throughout the life of the mentally retarded person. The complexities of mental retardation require a coordination of the facilities, programs and services of the various agencies of the State of Nebraska and those of the communities. Programs and facilities should be planned and provided as a part of a continuum of service to mentally retarded persons.

Each region has a board of directors and a central office responsible for the development of community based services. The State Office of Mental Retardation contracts with the regions for the delivery of service. Each is funded by a combination of county, state and federal monies. State guidelines and standards emphasize the principle of normalization.

One of Nebraska's six regions, a five county area of Eastern Nebraska, is administered by the Eastern Nebraska Community Office of Retardation. ENCOR is known both nationally and internationally for its innovation,

implementation of the normalization principle and quality control in programming for the retarded. The Program Analysis of Service System, a tool for performance assessment which stresses accountability and normalization, was developed by persons associated with ENCOR. PASS is now fairly widely used within the field of mental retardation. It is noteworthy that ENCOR staff has taught PASS to parents as one means of enhancing their role as advocates. ENCOR has developed a wide variety of community based services so as to individualize the services utilized by the retarded. Persons with all levels of retardation are served by ENCOR, including the profoundly retarded with multiple physical handicaps.

California

The last California hospital for the mentally retarded was completed in 1956. At that time the State's institutions served about 14,000 retarded persons. According to Pye (1974):

> ...questions began to be raised as to why California could serve its citizens only through this hospital type of system. These questions became more challenging as the State was pushed to include service concern and responsibility for the mentally retarded in its new community mental health system in 1957 and its expanding mandated educational system. It was, however, not until 1962, when the President's Panel on Mental Retardation published its report that we began to ponder and to formulate a State plan for services to a long-neglected and deprived population. This development induced a shift away from a patchwork of haphazard solutions to that of well-conceived and organized approaches. (p. 2)

California's first State plan for the mentally retarded was completed in 1965. That same year two Regional Centers were established. Three years later the Regional Center programs were expanded to cover the entire state.

> Until 1965, the State Hospital and post-hospital leave program were the only alternatives open to families, whether or not hospital care was needed by the individual or desired by his family. (California Bureau of Mental Retardation Services, June, 1969)

In 1968 the California Legislature authorized a comprehensive study which identified seven problem areas. According to Pye (1974) the study report noted the following problems.

1) Lack of a single agency with responsibility and funds to assure services to those in need
2) Lack of funds to purchase services
3) Lack of essential services in many parts of the state
4) Excessive reliance on the state hospital system
5) Lack of coordination and planning on regional and state levels
6) Inequities in fees imposed on parents of mentally retarded persons
7) Failure to fully utilize federal funds available for services for the mentally retarded

Additional legislation to correct these problems was introduced and passed. The Lanterman Mental Retardation Services Act of 1969 is the basic document now guiding the provision of services for the developmentally disabled. Seventeen Regional Centers are the key features of the service delivery system.

> In order to provide fixed points of referral in the community for the mentally retarded and their families; establish ongoing points of contact with the mentally retarded and their families so that they may have a place of entry for services and return as the need may appear; provide a link between the mentally retarded and services in the community, including state-operated services, to the end that the mentally retarded and their families may have access to the facilities best suited to them throughout the life of the retarded person; offer alternatives to state hospital placement; and encourage the placement of persons from the state hospital, it is the intent of this division that a network of regional diagnostic, counseling, and service centers for mentally retarded persons and their families, easily accessible to every family, be established throughout the state. (Lanterman Act)

In 1974, these 17 Centers were serving over 18,000 individual clients. The

institutional population has dropped to about 10,000. One of the unique features of the California approach is that all of the Regional Centers are private nonprofit agencies but primarily financed by state funds. Each works under contract with the State Department of Health.

> The Legislature finds that the services required of a regional center are of such a special and unique nature that they cannot be satisfactorily provided by state agencies. Therefore, private nonprofit community and local public agencies shall be utilized for the purpose of operating regional centers to the end that the unique relationship which these agencies enjoy with both the mentally retarded and their families and the providers of services in the community may enable the mentally retarded to receive service in the most direct, efficient and effective manner possible. (Lanterman Act)

The Regional centers are directly involved in the admissions to and discharges from the State Hospitals.

> ...except for those mentally retarded persons placed in state hospitals pursuant to the Lanterman-Petris-Short Act, no mentally retarded person shall be admitted to a state hospital except upon the referral of a regional center. Upon discharge from a state hospital, a mentally retarded person shall be referred to an appropriate regional center. (Lanterman Act)

Pye (1974) of the Golden Gate Regional Center in San Francisco notes that:

> We consider admission to the hospital system around the program need of the client, and the hospital as part of the community resources available to him. It is our policy clearly enunciated by our Board that we will not approve any discharge from the hospital unless an equal or better program is available. This has reduced discharges and highlighted gaps in community services...

Accompanying the development of Regional Centers and the emphasis on community based services have been changes in the role of State Hospitals. In contrast to the typical custodial institutions of the past, the Hospitals have become highly specialized. Greater emphasis has been placed on time limited care and training as a means of facilitating the retarded person's adjustment in the community. The Hospitals have also broadened their services to include developmental disabilities in addition to retardation.

THE FUTURE OF INSTITUTIONS

Judging from deinstitutionalization efforts such as those in California, Nebraska, and Connecticut, depopulation by one-third or even one-half appears both feasible and desirable. This raises questions about the future of institutions for the mentally retarded.

> Some budget and policy-makers are convinced that institutions are so outmoded that we can forget them, while we devote all resources to new community programs. However, institutions have existed for over a hundred years. It is unlikely that legislatures will simply throw away the buildings or that staff will disappear overnight. (P.C.M.R., 1974, p. 10)

How can states respond to this dilemma? The Presidents Committee on Mental Retardation (1974) suggests that institutions greatly modify their purpose.

> Institutions must come to be regarded as special purpose units. They can be re-oriented to offer emergency and temporary services; intensive care and treatment for the severely and profoundly retarded and for the multiply handicapped; respite care for families of the retarded; and highly specialized habilitation services for selected retarded persons on a non residential basis. (p. 11)

The Mansfield Training School in Connecticut is an example of a dynamic institution which has changed its program and purpose. Other retardation facilities, like the California Hospitals, have expanded their function to include service to other developmentally disabled persons, e.g., those with epilepsy, cerebral palsy and other neurological conditions.

Institutions in isolated, rural areas may find it extremely difficult to modify their purpose and programs. The Boulder River School and Hospital in Montana, for example, is located in a town of 1,300. Such facilities find it difficult to attract the skilled professionals needed to provide intensive training and treatment and their isolation and inaccessability make them unlikely locations for respite care and non residential programs.

DEINSTITUTIONALIZATION FOR THE SEVERELY AND PROFOUNDLY RETARDED

It is often assumed that large custodial institutions will always be needed for persons who have very severe handicaps. Alternatives are, however, possible. For example, Nebraska's ENCOR system has developed both community residential and supportive services for the profoundly retarded and for those who have multiple physical handicaps. ENCOR's Developmental Maximation Unit (DMU) in Omaha serves severely and profoundly retarded persons who may be nonambulatory and have multiple handicaps including seizures, physical impairments and sensory handicaps. According to a 1973 ENCOR publication, the DMU provides:

1) A combined residential and developmental program geared to basic developmental stimulation and to foster acquisition of self-help skills, ambulation, social-personal awareness and small group interaction.

2) Services to children who have complex medical challenges which need treatment and/or management models (such as intensive physical therapy) to further embellish their developmental potential.

3) Stimulation of the child's development so he can move on to and participate in more advanced programs in the future.

ENCOR staff believe that early intervention and stimulation such as that provided by the DMU can actually prevent the development of profound retardation. (Further descriptions of the DMU concept and related programs are found in Menolascino and Pearson, 1974.) Because smaller cities often lack sophisticated back-up services, the establishment of similar programs in non-metropolitan areas faces some obvious problems. This does not mean, however, that such programs could not be created in rural areas. In late 1973 a service for the severely/profoundly retarded was initiated in Wayne, Nebraska, population 5,379.

Undoubtedly, the potential of persons labelled severely or profoundly retarded has been underestimated. In dramatic fashion, Dr. Marc Gold of the University of Illinois Children's Research Center has shown that profoundly retarded individuals could be taught to assemble a bicycle brake within a few hours. One individual trained to complete this task had a measured I.Q. of 11. While they work slowly, these individuals often make fewer errors than normal factory workers performing the same task.

DEINSTITUTIONALIZATION IN RURAL AREAS

Deinstitutionalization efforts in rural states must grapple with a set of problems and issues somewhat different from those encountered in urban areas. Popp (1974) recently noted that the:

> ...special needs of rural areas seem to have been neglected in the nation's efforts to recognize and cope with the problems of mentally retarded persons. When the federal government arranged in 1964 for "comprehensive" state-wide mental retardation studies throughout the country, only a very few states ever mentioned the specific needs existing in rural areas. Yet rural areas still comprise a large part of the nation... (p. 129)

A 1966 Wisconsin project identified a number of special problems relating to the development of community based alternatives in rural areas. These characteristics need to be considered in planning for deinstitutionalization.

A. In a rural area the understanding and awareness of the retarded's needs and the subsequent impetus to serve him has suffered from the relative lack of exposure to publicity, information, and educational effort.
B. Services for the retarded have not developed in rural areas due to the mechanical problems involved in bringing people together in an area of low population density.

C. In a rural area there is often a lack of facilities such as day care, sheltered workshops, and special classes to serve the retarded.
D. Most rural areas lack diagnostic and treatment centers.
E. Rural areas lack an organizational structure for proper identification, treatment, and referral of the retarded and their families.
F. There is an extreme lack of trained professionals, such as psychologists, social workers, public health nurses and physicians, who can offer service to the retarded or their families.
G. The rural retarded and their families have long been unaware of any alternatives to strict custodial care in the home.
H. People in rural areas often have low expectations for their normal child, as well as the retarded, and are unable to see the value of training and education.
I. There is often a stigma attached to family counseling in a rural area, and the fixed point of referral may be located in a clinic or welfare department. Where little stigma is attached, such as the public health nursing service, this office is understaffed in a rural area.
J. Neighbors in a rural area often have less experience with and understanding of the retarded child than their urban counterparts.
K. Parents of the retarded in a rural area are often poor and cannot afford the cost involved in transportation or the child care necessary to attend parent group meetings or take advantage of counseling and diagnostic services for their retarded child. (cited in Popp, 1974, pp. 129-130)

If deinstitutionalization is to be accomplished in rural areas, planning and programming must be built upon rural culture, resources and characteristics. Strategies and programs developed in urban areas cannot be simply 'transplanted' into rural areas. Recent contributions to social service literature (Buxton, 1973; Segal, 1973; Koch, 1973; Mermelstein and Sundet, 1973) have identified several features of service delivery which are unique to rural areas. These also apply to community based programs for the mentally retarded. The provision of services on rural Indian reservations present an even greater challenge since the usual approaches to service delivery and notions of professional role are often contrary to the tradition of noninterference which is common to many tribes. (Good Tracks, 1973)

The Rural Community

Increasingly, the rural community resembles urban or suburban communities (Warren, 1972). While traditional urban-rural differences are becoming blurred, remnants of a rural culture still exist. Rogers and Burdge (1972) note that, "Rural persons (mainly farmers) exhibit certain attitudes and values which are different from those of urban persons." (p. 267) In areas where rural culture still persists, it must be considered in planning for deinstitutionalization.

Whether in an urban or rural area, new plans for the delivery of mental retardation services must take into account pre-existing human services. While it is true that rural communities have fewer formally organized professional services and agencies, it is a serious error to assume that a particular service is not being provided simply because a formal organization does not exist to provide that service (Ginsberg, 1973). Informal systems of service are common to rural areas. Patterson and Twente (1971) term these informal arrangements 'natural service systems' or 'natural helpers.' They tend to develop in the absence of formal services. These informal networks lack the sophistication and knowledge base of professionally organized programs but they do perform a valuable function and are usually 'supported' by influential citizens and community leaders. If a new formal plan for the development of human services poses a threat to these informal service structures, it may encounter considerable resistance. Wylie (1973) has observed, however, that this informal helping network may be more of an asset than a liability in developing a new formal service system in rural areas.

> Here is a mighty resource for the social planner--a pool of people accustomed to helping each other, a pool of people already accepted and identified by the community as helping agents, and people who can be easily identified...the challenge is to strengthen and expand this natural network by preserving the naturalness rather than imposing professional standards and norms. In other words, ...what we have there already may be quite good in its own right. (p. 26)

Despite some obstacles to change in rural areas, unique potentials are also present. One is the sense of pride and community spirit that exists in many rural areas. These elements are especially strong in relation to self-help activities and 'taking care of our own.' If new program ideas and plans are generated from within the community and are supported by respected citizens, the rural community is capable of rapid and surprisingly innovative action. On the other hand, plans or programs which are imposed upon small communities by 'outsiders' often meet resistance or fail to win support necessary for implementation. Because successful deinstitutionalization is so dependent upon community acceptance of the retarded and support for new programs, it is essential that local citizens, elected officials, parents and the 'natural helpers' be involved in any planning process which affects rural communities. Not only is their involvement necessary to win acceptance of new concepts and new programs but many of these same individuals are needed to form the nucleus of volunteers which are so necessary to rural programs. As one might expect, it is no small task for regional or state planners to strike a balance between a community's unique desires and values and the bureaucratic requirements of large scale social planning and funding constraints.

Regionalization

Essentially, a rural area is characterized by a large land mass coupled with low population density. Montana, for instance, is the fourth largest U.S. state in land area. It averages 580 miles in length and 315 miles in width. The states of Iowa, Indiana, Kentucky, Maryland and New Jersey could all 'fit' in Montana. Despite its physical size its 1970 population was only 694,409. These characteristics affect not only the nature of service delivery but also the cost of services. It is commonly assumed, for example, that a unit of social service costs about four times more in a rural area than in an urban area. The expense of time and travel are key factors which increase the cost of service. The small number of retarded persons in any one community makes it economically unfeasible for all communities to develop a total service system. Rather, services must be regionalized. Ideally, services should be planned and administered at the regional level.

A lack of coordination among community programs is a fairly common problem within all human service networks, including the mental retardation service system. A major cause of this problem is the multiple sources of private, county, state and federal funding utilized in the provision of services. Each source has guidelines which regulate the use of funds, the type of service which can be provided and eligibility. Coordinated funding appears to be a prerequisite for a coordinated service delivery system. As deinstitutionalization takes place many retardation services which were formerly state administered within a central institution have to be administered on a decentralized basis. In rural areas, this usually means the

utilization of multi-county organizations. Nebraska's highly successful regional programs operate within such interlocal structures.

Professional Resources

Rural communities can rarely support or afford a variety of professionals with specialized skills. Moreover, rural professionals have fewer opportunities to function as members of teams and have less access to consultation. For these reasons, rural human service workers, including mental retardation professionals, need to have a broader knowledge base and a greater range of skills than their urban counterparts. A very important set of skills are those related to the training and utilizing of the volunteers and paraprofessionals who must often carry heavy responsibilities in rural programs. Programs of continuing education and staff development are vital to programs which are staffed by many nonprofessionals and be professionals who must carry a wide range of responsibilities.

It is also important to note that the professional in rural areas must often assume roles quite unlike those he might have in a large metropolitan area. In comparison to urban areas, rural area residents place less value on professional credentials and 'expert opinion.' Whether or not a professional's suggestions are accepted often depend on his informal behavior and how he relates to 'ordinary people' in social situations.

Travel and Distance

A constant service delivery problem in rural areas is that of the physical distance between consumers and providers of service. Traveling teams of mental retardation professionals or roving program consultants are

commonly used in rural areas. For example, within Wisconsin's Portage Project specially trained teachers travel to the homes of preschool children with mental and physical impairments. It is, however, often difficult for traveling teams to maintain continuity of service and handle crisis situations. Moreover, constant travel tends to 'burn out' personnel and results in a fairly high turn over rate. In some instances, closed circuit TV, radio, and conference telephone calls have been used to deal with the problem of distance. Utah's Project TELEPAC, for example, utilizes the telephone. Further experimentation will be necessary in order to discover effective and feasible approaches to service delivery in rural areas.

Organizational Resources

Organizations provide the structures through which services are delivered. Basically three types of organizations provide the community based services which make deinstitutionalization possible: (1) public, (2) private nonprofit, and (3) private profit. While most retardation programs are publically financed, many are privately operated. For example, a recent nation-wide study of 475 community residential facilities for the retarded (e.g., group homes, hostels, boarding homes, etc.) showed that 47% were nonprofit and 32% were private profit organizations. Only 22% were publically operated. (O'Conner and Sitkei, 1973)

Purchase of service contracts are commonly used to provide public funding to private organizations. The purchase of service mechanism is essentially an arrangement whereby a public agency pays for service (e.g., foster care, training in sheltered workshops, counseling, diagnosis and

evaluation, etc.) rendered by private organizations. It allows governmental units to develop contracts with organizations, both profit and nonprofit, for the delivery of specified services and/or to develop and operate service programs. The mechanism is utilized, for example, in the Federal Title XX programs and in numerous state funded programs. Gilbert and Specht (1974) note that the purchase of service funding mechanism has both advantages and disadvantages.

> The major virtue of these forms of subvention to private and voluntary organizations is that they provide a varied means for starting government programs quickly. They avoid the rigidities of civil service and bureaucracy. Such characteristics are advantageous for public programs for small special groups of clients and for experiments or demonstrations.
>
> For the voluntary agency, the obvious advantage of these arrangements is access to the public coffers as additional sources of income. But they pay a price. To the extent that voluntary agencies are supported by government funds, they forfeit some degree of autonomy. Consequently, these agencies are limited in their ability to function as agents for the expression of new or unpopular ideas, as critics of public services, and as the guardians of pluralistic values. In the extreme, voluntary agencies may simply become an instrument of government policy. (p. 150)

In rural areas the flexibility of this mechanism is especially attractive because it permits the shaping and molding of programs to fit local situations, traditions and values. As previously indicated, programs designed and operated by local people are more likely to be accepted and supported by the community even though they are state funded. The community tends to view them as 'our programs.' By comparison, state operated programs have a harder time winning community support.

The purchase of service approach does, however, face some special problems in rural areas. The mechanism presumes that private human service

organizations exist and that they are capable of modifying or expanding their program so as to provide purchaseable services. Well established private agencies are rare in rural areas. Those that exist tend to be small and fragile. Many are operated and staffed by volunteers or have a paid staff of one or two people. Not infrequently, agency board members and key decision makers within these small organizations are unaware of successful programs in other parts of the country. Innovations or program changes are more likely to be based on the experience of a program in a nearby community than on ideas derived from national conferences, national trends or professional literature. Because they frequently lack adequate professional resources, these organizations are seldom capable of planning and developing the sophisticated training and behavioral shaping programs needed by the more severely retarded or those with behavioral problems.

In some cases, a new nonprofit corporation is created for the specific purpose of securing public funds for the provision of badly needed services. Unfortunately, a newly created organization must devote much of its time and energy to maintenance functions. Only after it 'gets on its feet' is it capable of devoting full attention to providing service. Thus, a new private service organization in a rural community may have a difficult time adhering to performance standards established by the state funding agency. This places state agencies in an awkward position of funding programs which leave much to be desired. To reduce these problems to a minimum, new service organizations should have ready access to technical assistance and professional consultation. As soon as possible, new programs should be required to meet performance standards such as PASS (Wolfensberger and Glenn, 1973) or the Standards for Community Agencies (Joint Commission on Accreditation of Hospitals, 1973).

FINAL COMMENT

This report has attempted to present an introductory overview of key concepts, problems and issues related to deinstitutionalization and the development of community based services for the mentally retarded. Factors which have given rise to the deinstitutionalization movement and factors which remain as barriers were briefly summarized. Several examples of deinstitutionalization efforts and an overview of desirable service delivery system characteristics were also presented. Special attention was given to key issues in rural areas.

On the basis of this brief review, we have reason to be hopeful but a long way to go. Many problems remain to be solved. Currently, we know more about what needs to be done and what can be done in order to achieve deinstitutionalization than about how to overcome some of the barriers which hamper rapid progress and the implementation of plans and concepts. Many of these barriers reflect myths about the mentally retarded and an ambivalence about their rights, their citizenship and their membership in the family of mankind.

Over the past decade we have seen the development of some outstanding and innovative programs for the mentally retarded. These developments have shown what can be done and that success is possible. We are also seeing a gradual change in public opinion toward and a greater acceptance of the person who is mentally retarded. Needless to say the change has been painfully slow, especially for the six million retarded persons in the United States who daily encounter a 'mix' of paternalism, discrimination, overprotection and rejection.

Far-reaching court decisions have laid the ground work for change away from the use and overuse of institutions. Most states have now established programs which will encourage deinstitutionalization and the expansion of community based services. Needless to say, however, many funding and administrative issues remain. Significant attitudinal changes must occur at the community or local level; changes which permit the retarded persons--especially former institutional residents -to live and function as citizens, neighbors, students and employees. Such changes will need to be solved community by community, neighborhood by neighborhood. More than ever before, local citizen interest and involvement is needed.

It is important to emphasize again the fact that an approach which works well in one community or area may not work well in another. Approaches to deinstitutionalization and the development of communtty based alternatives to institutional care, must be individualized and address local needs, values and traditions. This is especially true in rural areas.

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